

ERDERA — The European Rare Diseases Research Alliance

Comprehensive Overview:
People, Structure, Mission, Strategy & International Links

180+ Organisations | **37** Countries | **€380M** Budget through 2031

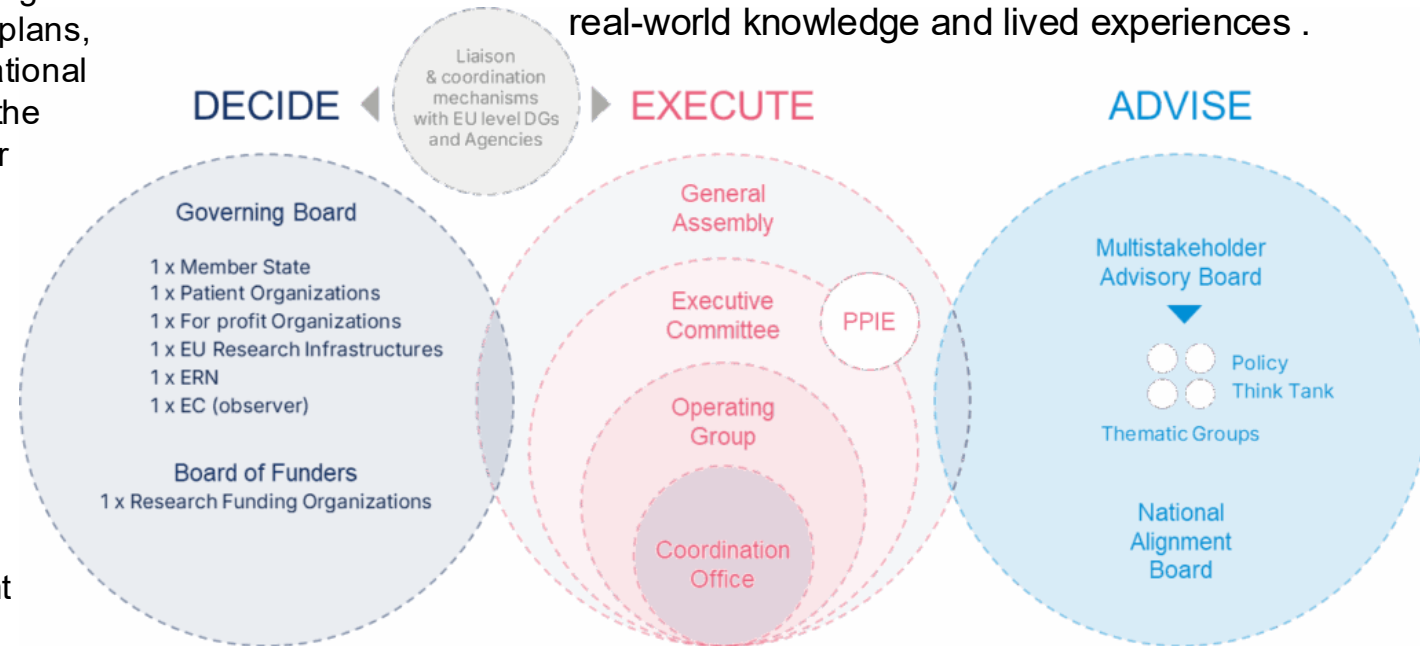
Governing Board (GB) is ERDERA's main decision-making body.

Composed of representatives from participating countries, patient organisations, industry, EU research infrastructures, the European Commission, and other key stakeholder groups.

GB is responsible for steering the overall strategic direction of ERDERA, approving annual work plans, and ensuring alignment with European and national policies. It also plays a key role in supporting the uptake of ERDERA outcomes and planning for sustainability.

Board of Funders (BoF) works alongside the **GB** but focuses specifically on decisions related to joint transnational calls (**JTCs**). It ensures financial coordination and commitment from national and European funders

Patient and Public Involvement and Engagement (PPIE) is an active partnership where patients, carers, and the public work alongside scientists to shape health research, contributing their real-world knowledge and lived experiences .



ERDERA's structure brings together national and international experts, funders, and stakeholders through a set of key bodies with defined roles.

Horizon Europe – International partners

Association to Horizon Europe is the closest form of cooperation with non-EU countries. Entities of associated countries can participate in programme actions on equal terms with entities of EU countries*. Indicative funding amount for Horizon Europe for the period 2021-2027 is € 93.5 B .

22 non-EU countries are associated with Horizon Europe

Albania	Kosovo	Ukraine
Armenia	Moldova	United Kingdom
Bosnia & Herzegovina	Montenegro	
Canada	New Zealand §	<i>From January 2027</i>
Egypt	North Macedonia	Australia [Pillar II]
Faroe Islands	Norway	<i>From 2026</i>
Georgia	Serbia	Japan [Pillar II]
Iceland	Switzerland	
Israel	Türkiye	
Korea	Tunisia	

New Zealand signed an association agreement with Horizon Europe on July 9, 2023, becoming the first non-geographically European partner country to join **Pillar II** ** of the EU's research and innovation program. **Australian organisations** have participated in 239 projects and as of January 2027 will transition to being an 'eligible entities'; granting direct, routine access to EU funding under **Pillar II**** on equal terms with EU Member States, and to lead project consortia. Testimony to the world-class calibre and exceptional quality of its research ecosystem, nearly one in four individual applications from Australian and New Zealand research entities is selected for participation in the programme - resulting in an impressive 24.39% success rate.



European **Rare Diseases**
Research Alliance

ERDERA GOVERNING BOARD

Chair: Hugh Dawkins (Principal Representative **Australia**)

Co-Chair: Iveta Hermanovska (Principal Representative **Slovakia**)

Louise Bicknell (Principal Representative, Aotearoa **New Zealand**)

Stephanie Hughes (Permanent Deputy, , Aotearoa New Zealand)

Christopher McMaster (Principal Representative, **Canada**)

Etienne Richer (Permanent Deputy, Canada)

July 2026



Co-funded by
the European Union

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Views and opinions expressed are those of the author(s) only and do not necessarily reflect those of the European Union or any other granting authority, who cannot be held responsible for them.

ERDERA: Our Global Scale & Investment



Diverse Partnership Network

Our mission is powered by a broad network of nearly **180 organizations** from **37 countries**, including:

- Funders
- Research Institutions
- Hospitals
- Research Infrastructures
- Patient Organizations
- Industry Partners



Extensive Global Reach

ERDERA spans **25 European Union countries** (except Croatia and Malta) and **numerous associated and non-EU countries**, fostering international cooperation (Australia, Canada, Iceland, Israel, Georgia, Morocco, New Zealand, Norway, Serbia, Switzerland, Türkiye, United Kingdom)



Substantial Financial Commitment

A significant financial commitment underpins our ambitious goals, with a total budget of approximately **€380 million**:

- **€150 million** investment from the European Commission
- Over **€230 million** contributed by participating countries and institutions
- **Every partner contributes** to our collective actions

ERDERA brings together diverse expertise and significant resources to advance its mission, demonstrating a strong commitment to global collaboration.

Towards a comprehensive RD Research Ecosystem

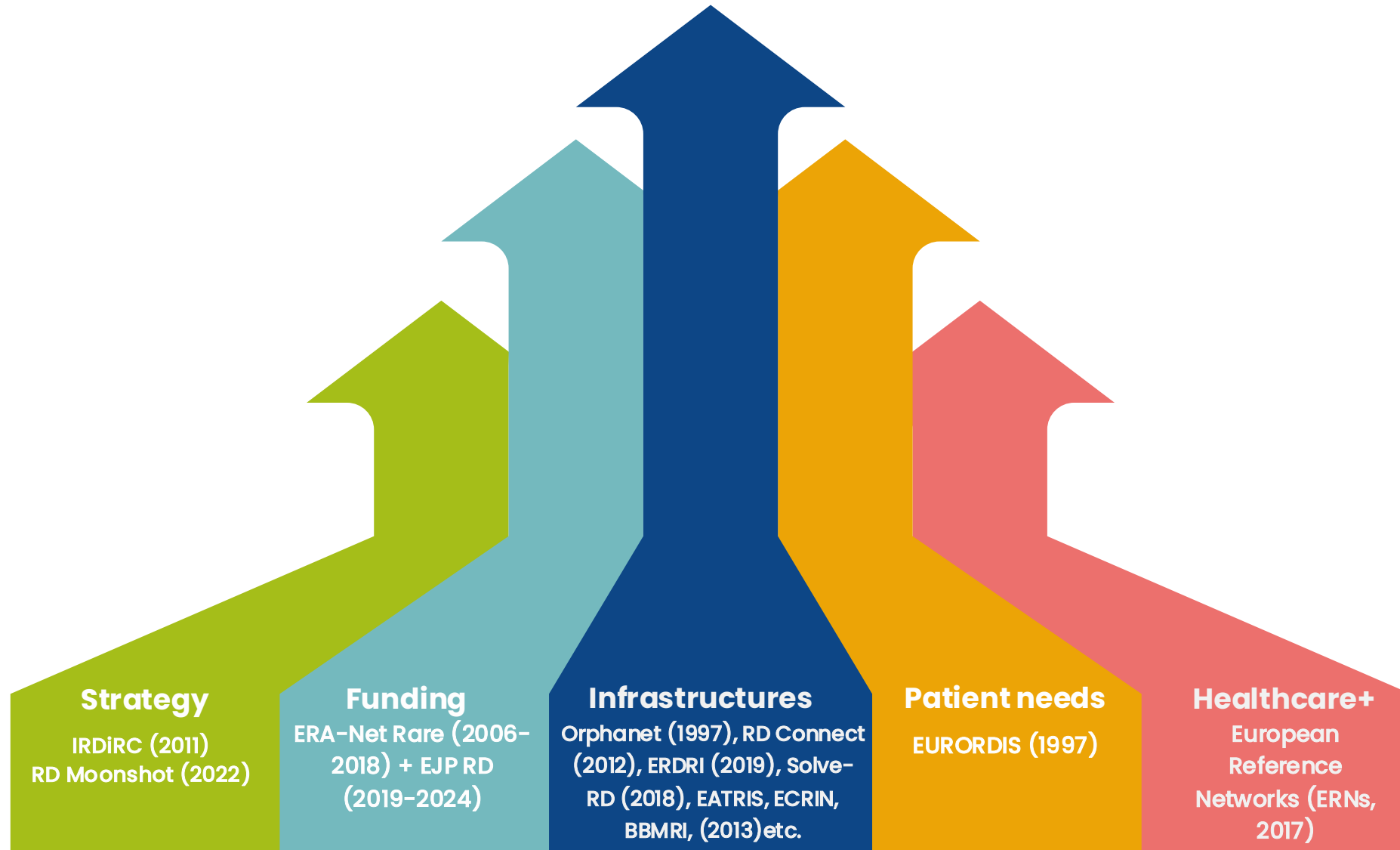


2019 - 2024

ERA-DE

European Rare Diseases
Research Alliance

2024 - 2034



Improving the health and well-being
of **30 million people** living with a **rare disease**
by making Europe a world-leader in RD research and innovation.



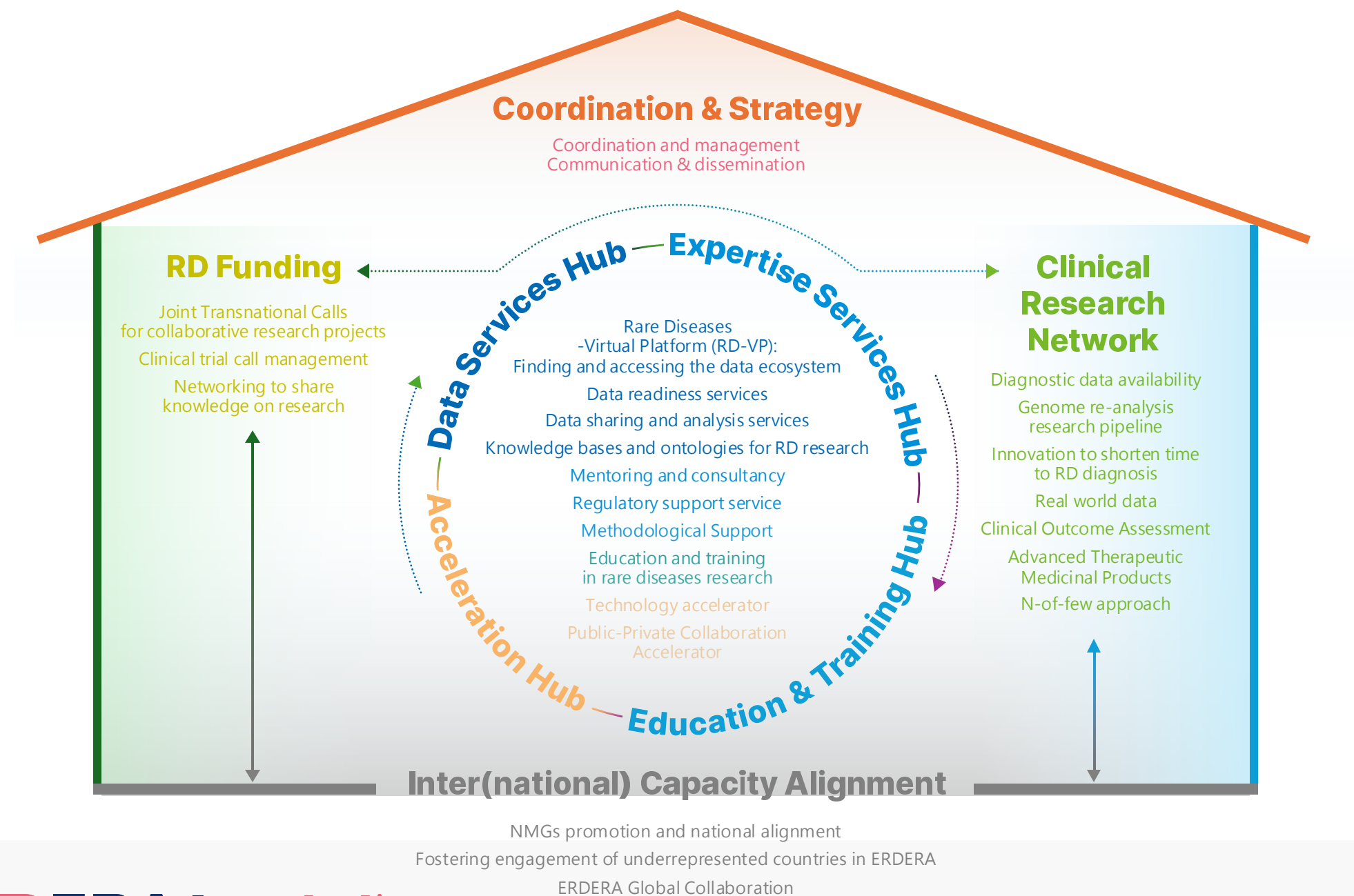
Diagnosis established or enrolment in systematic research in average **within 6 months** after coming to medical attention



New **effective therapies** **approved** in Europe and beyond, the majority of which addressing diseases without approved options



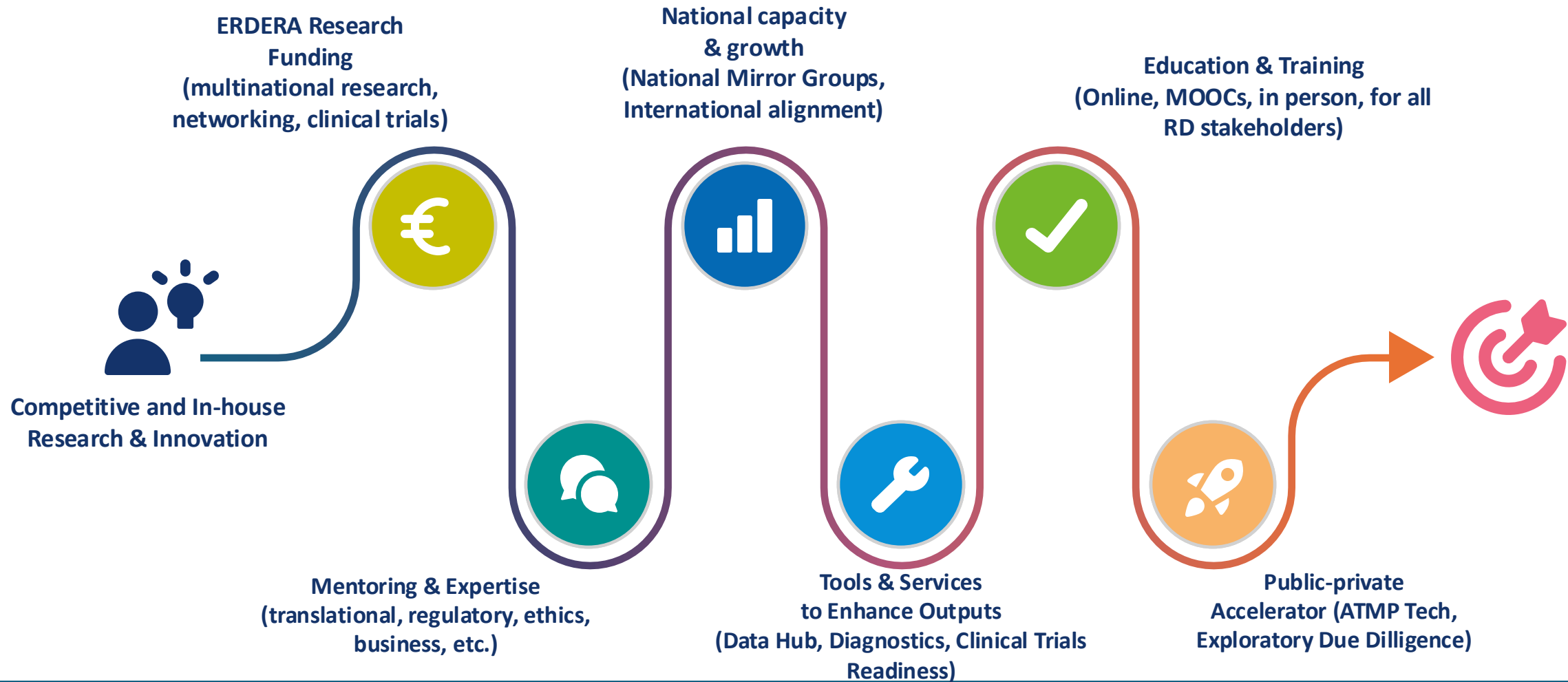
Better understanding of the **impact** of rare diseases on patients, families and society to improve quality of life



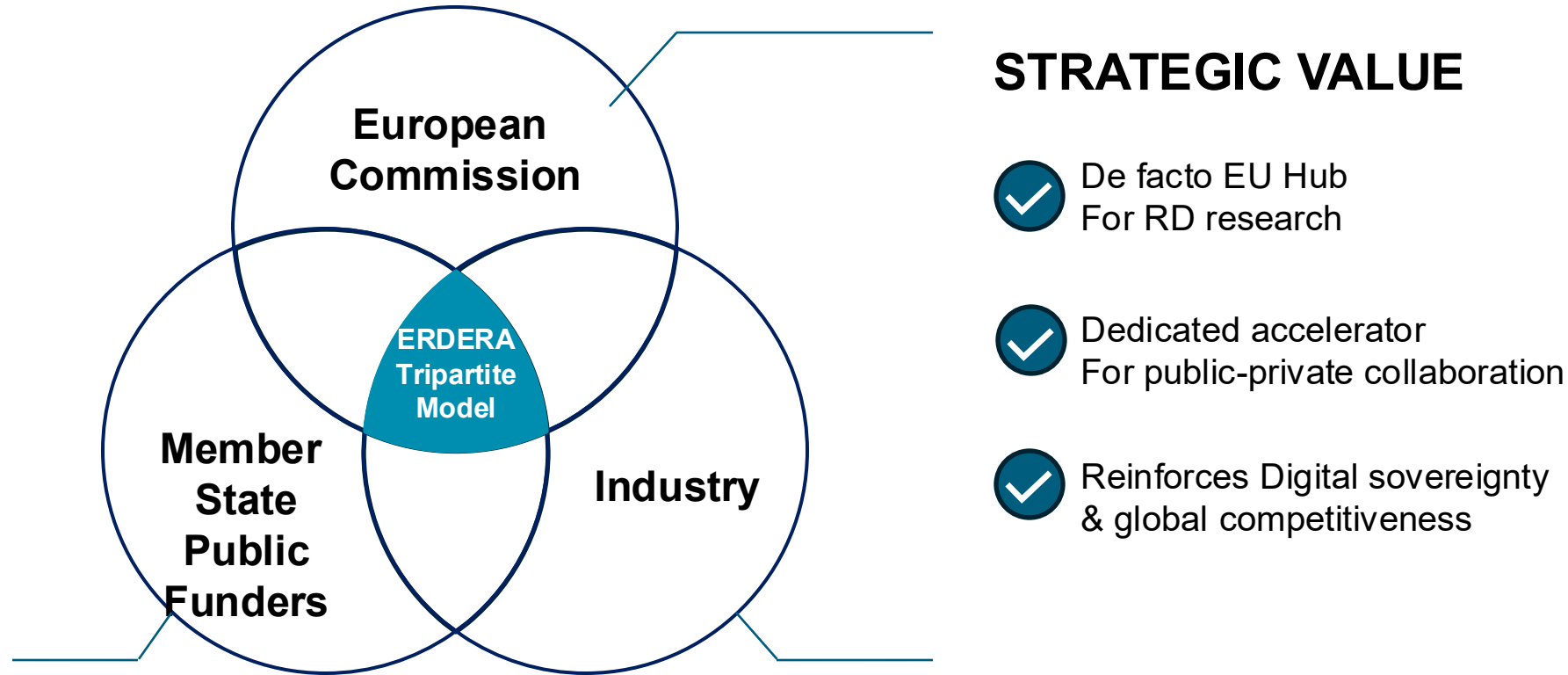


ERDERA in action

ERDERA's research & innovation support cycle



A fit-for-purpose model for European competitiveness



ERDERA is currently the only co-funded partnership operationalising the Tripartite model (desired for the next Framework Programme)

Frameworks for the Future



Parliamentary question - E-000886/2025
European Parliament

Action plan on rare diseases
28.2.2025

Seventy-eighth World Health Assembly – Daily update: 24 May 2025

24 May 2025 | Note for Media | Geneva, Switzerland



World Health Organization

First-ever rare diseases resolution underscores equity and inclusion

Member States today adopted a landmark resolution declaring rare diseases a global health priority in an effort to ensure that no patients are left behind. The Resolution recognizes that over 300 million people globally live with one of more than 7000 rare diseases, most of which begin in childhood and can lead to significant physical, emotional, and financial hardship.

The Resolution urges countries to integrate rare diseases into national health planning, improve diagnosis and care through universal health coverage, promote inclusive policies, and accelerate innovation, research, and access to affordable treatment. Importantly, the Resolution mandates WHO to develop a comprehensive 10-year global action plan on rare diseases, with measurable targets to guide progress toward equity, inclusion, and access to care for all affected individuals.



Rare2030
Foresight in Rare Disease Policy



**RECOMMENDATIONS
FROM THE RARE 2030
FORESIGHT STUDY**

THE FUTURE
OF RARE DISEASES
STARTS TODAY



RARE
DISEASES
INTERNATIONAL

**GLOBAL NETWORK
FOR RARE DISEASES**

Activity Report 2024



**High-Level meeting
on a European Innovation
and Care Ecosystem
for Rare and Complex Diseases**

9-11 December, Brussels

European Rare Diseases Research Alliance (ERDERA) logo
SJD logo
Rare Diseases International logo
Co-funded by the European Union

Supported by: epp, renew europe, European Commission

Platinum sponsor: ultragenix
Gold sponsor: Chiesi
Silver+ sponsor: BIOMARIN
Silver sponsors: DENALI, sanofi, ACADIA